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ABSTRACT

The position statement of the Association for Retarded Citizens (ARC) addresses issues in the design and delivery of programs for persons with mental retardation. An introductory section presents basic principles and philosophies underlying services, including integration, human rights, equal rights, normalization, and the developmental model. Then, specific issues are examined and positions of the ARC set forth: (1) rights of people who are mentally retarded; (2) the concept of least possible restriction; (3) work and employment related activities (productivity, work activity centers and sheltered workshops, and wages); (4) residential opportunities (in-home and out-of-home care); (5) guardianship; (6) behavior management; and (7) quality assurance. (CL)

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POSITION STATEMENTS ON PROGRAMMATIC ISSUES

A POSITION STATEMENT OF THE ASSOCIATION FOR RETARDED CITIZENS

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Adopted by the ARC National Board of Directors
1984

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PREFACE

Over the years, the Association for Retarded Citizens has developed a series of position statements which address various aspects of services for persons who are mentally retarded. The Association's positions are used to guide ARC national officers, staff and committees in their public statements and in setting priorities. They have also frequently had a significant impact on the development of programs in our nation. At present, there are a number of issues facing the Association which are of major significance to our members and to persons with mental retardation whom we serve. There is an evident diversity of opinion among ARC members on some of these issues, but the issues and the position statements contained in this document are the product of study and comment from the ARC state and local units over a two-year period and the dedication and hard work of national ARC volunteers who are past or present members of the ARC Program Services and Governmental Affairs Committees.

This effort began when the Program Services Committee developed a series of issues which were perceived to be of critical importance in the design and delivery of programs and services for persons who are mentally retarded. An issue/discussion paper was then developed and distributed to state and local levels for evaluation and comments. Their response served as a basis for further development of a series of position statements, which were once again reviewed by ARC state and local volunteers and staff. The Program Services and Governmental Affairs Committees then revised the position statements as they appear in this document and presented them to the ARC Board of Directors and convention delegate body for final approval.

The content of this document is divided into two parts: the "Preamble" which presents basic principles and philosophies that should underlie all programs and services for persons with mental retardation and an issue/position

section divided into seven specific programmatic areas. It is noteworthy that countless numbers of state and local volunteers and staff have provided thoughtful commentary toward the conceptualization and development of this document, resulting in a genuinely representative expression on the delivery of services to people with mental retardation. The ARC is especially indebted to the two committees who worked to finalize this effort:

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PREAMBLE

In developing its program policies on behalf of people who are mentally retarded, the Association for Retarded Citizens (ARC) bases its positions on certain underlying assumptions or principles. These principles in turn are rooted in both knowledge and belief. The purpose of this preamble is to summarize the major principles and describe their place in our evolving system of values.

SOCIAL AND SCIENTIFIC PROGRESS AND ITS IMPLICATIONS

During the past three decades, there has been extraordinary progress in the biological, behavioral and social sciences. The nature of memory, the processes of learning, the roles of neuro-transmitters and synapses in the brain are better understood. Many of the critical roles of genes and chromosomes in the causation of certain disabilities have been identified. The positive or negative effects of architectural design on human motivation and performance are now better appreciated. There is also an awareness of the psychological necessity for each person to have some sense of autonomy.

The application of new technologies has greatly enriched the lives of many people with handicaps. For example, computers have helped some people learn to communicate who have never been able to speak or write. Prescriptive teaching techniques have been successfully used with children previously considered uneducable. These advances offer hope for additional beneficial interventions in the future. New knowledge and technology have enlarged our understandings of what it is to be human.

The early 20th century concept of mental retardation as being incurable, unchangeable and primarily the result of inherited characteristics is now perceived to be invalid, as are

most of the traditional rationales for confining people who are mentally retarded in isolated institutions. The century-old "nature vs. nurture" controversy, while still alive has advanced to a new level with the recognition that individual characteristics are a unique result of the interaction between biological determinants, some of which are inherited, and all of the person's subsequent life experiences and educational opportunities.

In the social sciences, research continues to confirm that the human race is composed of people who cannot survive without mutual support and cooperation. Although we frequently refer to "independent adults," no man is an island and no human community is totally self-contained. The strength of civilizations is measured not only by respect for individual differences, but by a sense of responsibility of each for others, and especially for those who are the most vulnerable.

Contemporary research on human development brings into question the validity of segregation of persons who are mentally retarded as a public policy. Such a policy was widely practiced in the public schools during the first half of the 20th century, as well as in the conduct of public and private institutions. Residential schools and colonies for persons who are mentally retarded persisted long after orphanages had become discredited as settings unfavorable to normal child growth and development. One objective was to prevent procreation. Even after the eugenic movement lost its credibility, many people continued to defend vigorously the concept of segregation of persons who are mentally retarded. It was believed that they should be protected from society and that they would be happier with "their own kind." Only in the past two decades has this position shifted; the shift is based partly on the legal and constitutional arguments presented in the courts, and partly on findings that segregated settings often have a negative effect upon learning, growth and development. Thus, there is now a strong trend toward integrating persons who are handicapped by mental retardation with persons who are not mentally handicapped.

Integration means that persons with a variety of different characteristics are free to join or participate in some common activity. It is important that social institutions such as schools, churches, businesses, labor unions, and voluntary associations take pains to develop their capacities to accommodate diverse populations and to provide specific supports to individuals as necessary.

HUMAN RIGHTS AND CIVIL RIGHTS

Concurrent with the flowering of the sciences and humanities during recent decades, there has been a growing sense of a world community, shared by people of many cultures. The recognition of common human problems and concerns took on global dimensions during the development and promulgation of the United Nations *Declaration of Human Rights* in 1948, followed by the U.N. *Declaration on the Rights of Mentally Retarded Persons* in 1971, and of disabled persons in 1975. These declarations state principles which we in America share; we also have additional convictions based on our own unique national history.

THE WESTERN VIEW

Contemporary views on man and his societies have direct implications for people who are mentally retarded. Among those principles which now receive broad support in western democracies are the following:

1. People with handicaps, whether physical or mental, are human beings who have feelings, as well as human rights and responsibilities; they are to be valued and cherished as such, regardless of the degree of severity of their impairments.
2. Each human being is uniquely different from others, yet all share a common humanity; both factors must be considered together and both are equally important.

3. Every individual is capable of learning, growth and development and each should be approached with a positive expectation that desirable change can be accomplished.
4. All individuals share the right to participate in community life and to use community resources along with other people. This includes the freedom to enjoy a chosen life style that is generally compatible with the norms of the society of which the individual is a part. In addition, each person should have access to specially adapted opportunities which will maximize his skills and competencies and which will, in turn, enable him to take advantage of his freedoms in culturally acceptable ways.

The American Idiom - Equal Rights

In 1776, the leaders of the new America declared with passionate conviction that all men are created equal and have inalienable rights. The Constitution and early laws adopted by the Congress fell far short of implementing these high ideals. However, each generation since has made some progress in translating into constitutional law and practice the ideal of "one nation, under God, with Liberty and Justice for all" --a nation with a growing commitment to freedom, equal justice and compassion.

The Association for Retarded Citizens of the United States invokes on behalf of these same citizens certain constitutional principles:

1. All persons born or naturalized in the United States are citizens with the same fundamental rights; all persons living in the United States are entitled to equal protection under the laws of the United States and of the several States.

2. Among the rights protected by our laws are certain cherished freedoms:

to associate with companions of one's choosing
to pursue one's own happiness while respecting the rights and interests of others,

to speak out and to advocate for one's own views,

to be protected from arbitrary confinement or forced segregation or forced labor.

to learn, and

to seek satisfying work.

3. Citizens whose handicaps are so serious as to interfere directly with their enjoyment of fundamental legal rights should, as a matter of law as well as conscience, be accorded necessary accommodation to enable them to overcome, as far as possible, the physical, social or legal barriers which limit or preclude their exercise of these rights. The boundaries of what is reasonable or possible are not static but will expand as knowledge increases.

The concept of "equal protection for the unequal" has special meaning for persons with disabilities. Many, especially those with mental retardation may lack some if not all of the skills to represent their own interests. Only gradually has the legal community begun to recognize that some individuals are not equal before a law that is blind to their relevant disabilities. Today, "equal protection" and "equal opportunity" are no longer interpreted in a way which assumes that all people start from the same base line. Rather, current philosophy holds that circumstances should be responsive to recognized individual differences.

Each protection in the 1980s means that people who are mentally retarded now share with others the same basic rights, including:

a free appropriate public education,

the right as adults to enter the labor force

the right to live in the community,

the right to speak for one's self,

the right to move from state to state, as well as within states,

the right to privacy,

the right to counsel and to a fair trial, and

the right to choose whether to exercise a particular right, all in the context of a society in which the liberties of each must be fairly accommodated to those of all.

It should be remembered that, important as they are, rights alone do not guarantee a full life. There should be room for compassion, spontaneity, diversity, tolerance and common sense.

People Who are Retarded in the Context of Human Services

The way in which persons who are mentally retarded are viewed and served is largely dependent upon the philosophical orientation of service providers and the larger society. As traditional misconceptions based upon fear and ignorance give way to modern program philosophies, program strategies emphasize the similarities between hardi-

capped and non-handicapped persons, rather than their unique differences. The two major philosophical approaches which have gained worldwide acceptance are the **normalization principle** and the **developmental model**. These in turn have undergone and are undergoing some transformation as we experience their realization in practice.

The developmental model was first described in detail by Dr. Philip Roos in a major address at the 1970 ARC Annual Convention. As applied to a person who is considered to be mentally retarded, it recognizes a capacity for physical, intellectual and emotional growth, even in people with the most serious impairments. The use of the developmental model is particularly important in approaches to persons with developmental disabilities such as mental retardation. By definition, developmental disabilities are long-term disabilities originating early in life and affecting many of the ways in which children grow and adults function in society.

The positive concepts inherent in the developmental model are based upon significant research findings on the nature of child development, both biological and psychological, on the importance of early stimulation, on the success of prescriptive teaching methods, on the "plasticity" of the brain, and on human adaptability throughout the entire life cycle. These developments in turn support our confidence that forthcoming research will provide techniques applicable to impairments which still appear intractable.

The developmental model calls for emphasis on the following three goals for persons with developmental disabilities:

- to increase the complexity of the individual's behavior,
- to increase the individual's ability to control his or her environment, and
- to maximize those qualities which are perceived as normal or human.

To achieve specific personal objectives consistent with these goals, a person with mental retardation, like others, needs access from birth on to good health care, including treatment to alleviate any specific physical or sensory impairments or nutritional deficiencies which may further impede growth and development. Additionally, children and adults, including those who are mentally retarded, need age-appropriate opportunities to make decisions, to exercise choice, to take reasonable risks, to accept the consequences of their own behavior, and to associate comfortably with peers and other people who differ in age, appearance, interests, beliefs, abilities and life experiences. Thus (unless specifically contraindicated on an individual basis), integration in various settings (e.g., in school, at work, and housing in the community) is seen, not as an end in itself, but as one means of stimulating development through broadening experiences for both handicapped and non-handicapped persons.

The developmental model has been frequently cited as a counter measure to the "medical model." Such a dichotomy is an over-simplification which became popular at a time when the training of physicians emphasized their capabilities in treating and curing acute conditions, often giving them a pessimistic view of patients with chronic conditions. Ironically, these same physicians were historically given the role of overseeing the institutional care and treatment of persons with long-term disabilities, such as severe mental retardation. It was a role for which they were often ill-prepared psychologically as well as technically. Thus, service models based on psychoeducational concepts became the preferred choice of parents and others who sought help from professionals with a more optimistic outlook. Recent advances in medicine, especially in neurology and physical medicine, are now being incorporated in more comprehensive approaches to habilitation.

Today the developmental model is generally implemented through interdisciplinary teamwork, involving persons professionally trained in health and human services, as well as education and psychology. In such an approach, the skills of

professionals, paraprofessionals and parents or advocates are jointly directed toward the achievement of developmental goals and objectives set prescriptively for and with each individual and his family.

The normalization principle dovetails neatly into the developmental model. The former, like the latter, calls for service settings and living arrangements which enable individuals with handicaps to associate and interact with persons who are not considered handicapped, but normalization has other implications as well. The concept originated in Scandinavia and was refined and expanded by Wolf Wolfensberger in 1972 and by Wolfensberger and others in 1977 and 1980.

One definition of the normalization principle used recently by Wolfensberger (1980) is as follows:

Utilization of means which are as culturally normative as possible, in order to establish, enable or support behaviors, appearances, experiences and interpretations which are as culturally normative as possible.

Wolfensberger cautions that "normative" means "having value" in the particular culture, not "being normal" or average.

Millions of words have been written about this principle in the past ten years. This is testimony both to the usefulness and to the complexity of the concept. It was originally devised in large measure to counteract the undesirable effect of "negatively valued differentness." For example, one of its several intended benefits is to reverse the downward spiral often experienced by people who, being perceived negatively, are therefore denied opportunities with the result that they slip down the social scale and become still more negatively perceived, the victims of "self-fulfilling prophecies." There are also a number of positive corollaries of this principle which are reflected in particular positions

adopted by the ARC. Normalization, integration (or mainstreaming) and "least restriction" have all come to be seen as mutually complementary doctrines, parts of a whole, to be interpreted in context.

In looking to the future the concept of normalization in the '80s is now moving through the usual cycle of adoption-in-theory (currently achieved) to at least partial adoption-in-practice (Flynn and Nitsch, 1980). However, the concept itself must evolve with time, and now, after a decade, new formulations may be needed.

In *Megatrends*, John Naisbit (1982) suggests that in the fast-moving, knowledge-based, post-industrial society of the future, there will be less reliance on representative democracy and more on participatory democracy. There will be a diffusion of responsibility which will permit each individual to contribute some small, unique piece to the mosaic. Amidst such social diversity, respect for individual differences can grow and is growing; cooperation can once more have a greater value than competition. The time may be right for persons with disabilities to ride this tide toward fuller participation.

THE RIGHTS OF PEOPLE WHO ARE MENTALLY RETARDED

ISSUE

The fundamental rights of people who are mentally retarded are not yet fully acknowledged or secured, despite the vigorous efforts of advocates to help them achieve the same basic human and constitutional rights as other human beings. There is also the controversial question of whether special rights, protections, and privileges are required or desirable.

Some believe that children and adults who are mentally retarded have a "right" to more services and support than non-handicapped citizens. Because of their handicaps, special services are necessary to allow these individuals to fully exercise their basic rights. Others challenge the validity of this stance in terms of "competing equities." Is it normalizing (and consistent) to demand equal protection and treatment while at the same time pressing for "special privileges?" It is also argued that society simply lacks the resources to provide all of its citizens with the benefits that may be desirable.

A related concern or issue is whether special legal protections should be provided for adults and children who are mentally retarded. One question is the protection of rights through guardianship. (See position statement on guardianship.) Another is the question of providing special legal protections against parental decisions which may run contrary to the child's best interests. These questions become more critical when they arise in situations which involve the placement (e.g., residential, educational or vocational) of a person who is mentally retarded or the withholding of potentially life-saving medical treatment because of perceived severity of the individual's intellectual handicap.

Legitimate differences of opinion may arise between parents and professionals or advocates concerning the courses of action which best protect the interests of a family member who is mentally retarded. One view is that the vast majority of parents actually know their offspring better than anyone else, have their best interests at heart and are in a better position to make critical decisions than professionals or advocates. A second view is that parental decisions may at times run contrary to a child's best interests and persons not intimately and emotionally involved may be in a better position to make important decisions on a child's behalf.

POSITION

The ARC believes persons who are mentally retarded have the same legal, personal, and civil

rights under the federal and state laws as any other citizen. These rights, as for all citizens, should never be limited or restricted without compelling state interests and due process.

Persons who are mentally retarded are entitled to the same services and protections as other citizens. Adults should be allowed to fully exercise their citizenship rights and live as independently and normally as possible. When necessary, in light of the nature of their special handicaps, services and protections should include those, similar to those offered to other disadvantaged people, which allow individuals to exercise their rights in a meaningful way.

In accord with this position, the ARC believes that the rights and protections of minor children who are mentally retarded and their parents are no more or no less than those for other children and their parents. The same presumptions pertain in favor of parental obligations and responsibilities to make decisions and act on behalf of their minor children. As with any child, parents of children who are mentally retarded do not have the prerogative to make decisions or take actions which threaten the health or safety or lives of their children. In such situations, the same legal mechanisms -- constitutional, legislative, administrative, and judicial -- which protect the lives and safety of all children should be vigorously and expeditiously pursued.

The ARC strongly encourages the establishment of human rights committees to help ensure the welfare of persons with mental retardation.

LEAST RESTRICTION

ISSUE

The principle of least restriction is based on a legal doctrine requiring government to interfere as little as possible in

the private lives of citizens, while maintaining a reasonable concern for the public interest. The concept was first applied in the field of mental retardation as a challenge to the practice of isolating children and adults who are mentally retarded in residential institutions. This concept underlies the federal Education for All Handicapped Children Act (P.L. 94-142) which stipulates that children who are handicapped should be educated with children who are not handicapped to "the maximum extent appropriate." The basic rationale that has been used for placing children who are mentally retarded in "least restrictive environments" is to enhance their personal development and minimize interference with individual freedom. A secondary aim is to assist non-handicapped individuals in learning about and developing an appreciation for all fellow individuals regardless of physical, mental or psychological condition.

This principle has been established as a key factor in assessing the appropriateness and effectiveness of programs, services and settings for persons with mental retardation. However, there is considerable confusion and controversy concerning the process by which the principle can be converted from theory to practice.

POSITION

The ARC believes that there are three inter-relating goals associated with the concept of least restriction: (1) to enhance personal development; (2) to promote individual freedom; and (3) to enhance the interests of society. The effects of each goal should be viewed as being represented on a continuum ranging from total interference to maximum enhancement.

The decision to place an individual in a specific setting must include a judgment that it is "least restrictive" based on the analysis and weighing of the impact of the setting on each of the several interacting goals. The decision-making process should involve a team

consisting of professionals, parents and other advocates and, when appropriate, the individual who is mentally retarded.

When making a judgment as to what constitutes an appropriate least restrictive environment, the following should be emphasized: if the environment interferes with an individual's personal development, it is to be considered restrictive even if it does not inhibit his present individual freedom. For example, if the environment places unwarranted educational, psychological or emotional burdens on the individual and makes development unduly difficult, then the environment is restrictive. Judgments should be based on the future as well as present benefits for an individual who is mentally retarded. For this reason, environmental settings and circumstances should be evaluated at least annually to ensure continuing appropriateness and effectiveness.

The ARC believes that the concept of least restriction should be applied to all programs and services and all environmental settings for persons with mental retardation. This would include but not be limited to educational, residential, vocational, social, recreational, day care programs, services or settings.

WORK AND EMPLOYMENT RELATED ACTIVITIES

ISSUE: PRODUCTIVITY

The ability to work and become independent is one way to obtain the approval of society, as well as to enhance an individual's own self-esteem.

Most people who are mentally retarded are capable of becoming productive. Yet many, especially those with severe mental retardation, remain in overly sheltered settings for indefinite periods of time, engaged in deadend

make-work activities of little value to society or themselves. It has been demonstrated that individuals who are moderately, severely and profoundly mentally retarded individuals typically served in adult activity programs can learn vocational skills which were once thought to be too difficult for them (Bellamy, Peterson, and Close, 1975; Crosson, 1966; Gold, 1972; Loos and Tizard, 1955). However, low expectations prevail in spite of demonstrations which show that people who are severely mentally retarded can, if properly trained, perform a variety of jobs competently.

POSITION

The ARC believes that the vast majority of persons who are mentally retarded have the capability, or can be prepared, to enter the competitive labor market or to perform in well-paid sheltered work situations, earning at least the minimum wage. Adults with mental retardation must be provided the opportunity to receive appropriate vocational training, to receive assistance in securing appropriate employment and to participate in real work.

Movement into more work-oriented programs should be an ongoing goal. In this regard, **the ARC believes that vocational programs must be planned and conducted in a manner consistent with the jobs that exist in the community as well as those that are likely to be available in the future.**

Incentives should be provided to employers who offer employment opportunities to persons with mental retardation. Examples of incentives are reimbursement or tax deductions to employers for excess costs in initial employment, on-the-job training, or adaption of the job or work place.

The ARC supports the concepts of work stations in industry. The developers of work stations in industry attest to the importance of built-in normal setting expecta-

tions and the crucial role of non-handicapped individuals as "model workers." Also essential are appropriate training technology, job analysis, and adaptive devices for workers who find learning job tasks more difficult when customary methods are used.

The ARC strongly encourages the use of high technology to increase employment opportunities for adults who are mentally retarded through the adaptation of machinery, job redesign and the control of health and safety factors. Employment opportunities for persons who are mentally retarded can be greatly increased if emphasis is placed on wide dissemination and utilization of new technology in both competitive and sheltered settings.

Work-ready persons who are mentally retarded should not be denied access to government-sponsored employment and job programs simply because they are mentally retarded. Government-sponsored work retraining programs should be open to individuals who are mentally retarded who are otherwise capable of working.

ISSUE: THE ROLE OF WORK ACTIVITY CENTERS AND REGULAR WORKSHOPS IN VOCATIONAL TRAINING

The number of persons in sheltered workshops (also known as regular workshops) and work activity centers has increased markedly in recent years. Department of Labor statistics indicate that nationally there are almost 4,500 sheltered workshops serving approximately 190,000 handicapped persons. Over 75 percent of these facilities are work activity centers, which serve 132,000 clients whose measured output is well below accepted norms. Approximately two-thirds of our nation's sheltered workers are persons who are mentally retarded.

Regular workshop employees are expected to produce at 50 percent or better of the standard rate for non-handicapped workers. Work activity centers are intended

to provide "therapeutic activities" for individuals whose productive capacity is so severely limited that their productivity is considered "inconsequential." However, many individuals presently working in work activity programs are not "inconsequential" workers. According to the 1966 amendments to the Fair Labor Standards Act, a work activity center must be an independent facility or physically separated area(s) of a regular workshop.

Most states have developed several employment options for persons who are mentally retarded. Those individuals who are not considered ready or able to benefit from formal job preparation are referred to work activity centers which will get the person "ready" to benefit from regular workshop programs and, if possible, competitive employment. The Department of Labor reported in 1979 that less than three percent of the individuals served in work activity centers in 1976 moved on to regular workshops or competitive employment.

POSITION

Regardless of the severity of the handicapping condition, all persons who are mentally retarded should be provided the opportunity for work related training. Individuals who are mentally retarded should enter the training program most suited to their needs.

Workshops should develop a wide variety of training and work opportunities to maximize work skills, pay and placement in outside employment. Transitional training programs or extended sheltered employment in workshops should be designed to offer a wide variety of tasks and opportunities and systematic advancement from simple to complex job situations.

Existing practice (regulations) should be modified to permit employees in work activity centers to be integrated with employees in regular workshops to enhance opportunities for increased productivity of both groups. Attitudes and program approaches have

shifted to the point where requiring segregation of workers into separate activity centers and regular workshops is neither justifiable on programmatic grounds nor practical on grounds of efficient use of resources. Whatever the setting, individuals with mental retardation should receive vocational and other habilitative services based on their individual needs. They should be able to participate in a common program without segregating lower producing from higher producing workers.

Services should be provided which emphasize training for work to increase productivity of all individuals with mental retardation. These individuals should receive vocational training that prepares them for jobs that will be available following the training. Placements should be selectively based on an individual's projected capabilities, not on what job happens to be most available.

Workshop managers who lack business skills should have available to them consultation and training to develop improved business and production methods. Any business competing in the open market must maintain the technology necessary for efficient operations and productivity.

ISSUE: WAGES

Data on job placement, wages and vocational programs provide a bleak outlook for people with mental retardation currently in regular workshops and work activity programs. According to the U.S. Department of Labor Sheltered Workshops Study in 1979, workers who are mentally retarded earned a mean hourly wage of \$1.21 in regular workshops, 39 cents in work activity centers, and 61 cents in training and evaluation programs. During the period of active rehabilitation, trainees in workshops typically earn very low wages. Unfortunately, many clients remain in the "trainee" status for long periods of time with little or no opportunity to increase their wages. According to federal law, clients in regular workshops should be paid at least 50 percent of the minimum wage. However, approximately

half of the handicapped workers in regular workshops are covered under special exemption certificates (e.g., exemptions for training or evaluation or individual rate). The result is that employees generally earn less than half the minimum wage. On the other hand, some workers may be intentionally deprived of the opportunity to be placed in competitive employment by regular workshops because of their ongoing commitments to meet production contracts.

POSITION

The ARC believes that adequate safeguards, including standards and enforcement procedures, should be established and implemented to protect sheltered workshop employees from economic exploitation. Wages must be commensurate with those paid for similar work performed by non-disabled workers. To this end, workshops must submit to periodic outside evaluations. The periodic reviews should ensure that piece rates are based on reasonable production standards, hourly rates are based on adequate production evaluations, and prevailing wage rates are adequately documented.

The Department of Labor should review its special exemption policies to ascertain if disincentives exist which prevent workers from increasing their productivity.

Persons whose productivity, after completing training and being given appropriate supports and accommodations, is not sufficient to justify a competitive living wage, should have their incomes supplemented through the income maintenance and associated health care systems. Financial supplementation should be provided in a manner that rewards efforts to work and encourage achievement. The Department of Health and Human Services should review its relevant programs (e.g., the various titles within the Social Security Act) to ascertain if those programs create disincentives for persons with mental retardation for full employment opportunities.

RESIDENTIAL OPPORTUNITIES AND LIVING ARRANGEMENTS

ISSUE: IN-HOME CARE

Only a small proportion of children and adults who are mentally retarded are living in formally organized residential facilities. The majority live with natural families, foster families or on their own, singly or as married couples. However, much more attention is directed to out-of-home arrangements such as group homes or intermediate care facilities, whether public or private. Families who maintain a disabled child or adult at home are faced with problems of continuous care and supervision over extended periods of time, some of which can be alleviated by appropriate supportive services such as home aid, respite care, training and counseling. Such supportive services are lacking in many communities. Frequently public policies are more liberal toward a child (and his or her parents) if the child is placed outside the natural home.

POSITION

For most children who are mentally retarded as for most normal children, growing up in a natural or adoptive family home and attending the neighborhood school is the most normal and least restrictive living arrangement. **Every effort should be made to encourage and assist families to maintain their children in this environment by alleviating the extra financial, emotional and practical burdens to which families may be subjected. Supportive services should be offered on an individualized and prescriptive basis.**

For those families and individuals with mental retardation for which living at home is no longer desirable, a range of suitable alternatives should be available in the community.

ISSUE: OUT-OF-HOME CARE

During the past two decades parents and professionals have become more knowledgeable about the developmental potentials of persons who are mentally retarded. As a result, extensive efforts have been directed toward improving institutional settings. Smaller living units with active programming have been developed. Increased numbers of staff and better staff training have been achieved. The normalization principle and the developmental model have become the philosophical basis for the design and delivery of services within many institutions.

The most recent trend has been the development of residential service options as alternatives to the traditional institutional facility. Many communities across the country are now meeting the residential needs of persons who are mentally retarded with small community-based homes or other supervised arrangements in apartments and town houses. Living in community settings has provided the opportunity for persons with mental retardation to benefit from the full array of generic services which are available to the larger population and to enjoy the most normalized life style possible.

Currently there are major differences in opinion concerning the need and importance of the institutional and community approaches for providing residential care. Controversies continue to exist regarding the direction of tax dollars, the accountability of the community system, and the quality of support services.

POSITION

ARC policy supports the establishment of arrays of residential facilities and services for children and adults who are mentally retarded. Program settings must provide environments that support the developmental and social needs of the individual and enable them to experience a life style that is as close to normal as possible.

The ARC believes that the following principles should be applied toward the achievement of the basic policy:

I. Community Planning:

- 1) Each state and community should establish a plan for providing various residential opportunities and support systems that will meet the different and changing needs of individuals with mental retardation of all ages.
- 2) Federal, state and local financial support should be secured for developing necessary community services and support systems including residential options, work training, social skill training, health care, clinical support services, recreational opportunities and assessment, counseling and case management.

II. Individual Placement Requirements:

- 1) The selection of a residential facility should be based upon individualized program plans which reflect the special needs of persons who are mentally retarded.
- 2) Residential homes should be like others in the neighborhood in terms of size and appearance. They should be dispersed throughout the community, rather than congregated in one neighborhood.
- 3) Persons with mental retardation of all functioning levels, as well as those who have multiple handicaps, physical disabilities and emotional disturbances, should have access to community residences and services.

- 4) Individuals with mental retardation have a right to express their feelings and interests when a placement is being considered, and each should have the opportunity to participate in the decision-making process, as appropriate.

III. The Transitional Period - Institutional Phase-Out:

- 1) Large multi-purpose institutions are still providing services to many individuals. The use of institutions should be phased out because of their lack of success in providing essential developmental opportunities needed by persons who are mentally retarded. During this phase-out, quality care must be assured for persons residing in institutions during the transitional period.
- 2) The development of alternative residential services should be accelerated in those communities or geographical areas that are heavily dependent on the institution model of care. In this regard, the ARC has a responsibility to help communities learn about optional residential opportunities and how to plan for achieving them. Such assistance may include providing information about models of appropriate residential alternatives, and/or assistance in the development of community services plans and funding mechanisms.

In order to achieve this ideal, resources of the ARC should be directed toward the preparation of community opportunities, the development of appropriately trained program staff and the enlistment of cooperation among all resources that are needed to implement this policy consistently.

GUARDIANSHIP

ISSUE

The majority of adults who are mentally retarded can manage their own affairs with informal assistance and guidance from family, friends, citizen advocates, and service agency support personnel. The adult acting on his own behalf must have some ability to foresee and appreciate future consequences of present-day decisions, actions or failure to act. Consequently, some persons may require the more formal protection and assistance provided by a guardian who is appointed by a court and is legally empowered to act on their behalf. This need will vary from requiring assistance in limited areas -- for example, financial planning or management -- to, for a very few, full guardianship of the person and property.

POSITION

The appointment of a guardian or trustee is a serious matter involving the deprivation of a person's independence and rights. **The ARC believes the decision should be made only to enhance rather than limit a person's ability to exercise his or her rights.** Appointment of a guardian should be made only to the extent necessary for the welfare of the individual and not for the convenience of the family, the service system, or society.

Each state should adopt procedures allowing a range of limited guardianships. The restrictions on the ward's rights and decision-making powers should be confined to those areas in which the ward is demonstrably incapable of appreciating the serious consequence of his or her decisions or lack of foresight.

In appointing a guardian, the courts should consider those qualities needed by the guardian to fill this role effectively. Those qualities would minimally in-

clude an understanding of mental retardation and the individual and an ability to relate to the ward so as to understand and represent his or her needs and desires effectively. Barring evidence to the contrary and if they so choose, parents should be viewed as qualified and concerned guardians for their adult offspring who are mentally retarded.

The ARC believes the continued necessity for guardianship should be evaluated annually, and at all times guardians should encourage their wards to exercise choices for themselves even in those areas where the guardian has authority to intervene. Since guardianship represents a transfer of the responsibility for exercising an individual's rights, adequate safeguards are needed to assure the individual retains as much independence as possible. Guardians should be accountable to an appropriate authority to ensure that abuse does not occur. At the same time, a legal system must not be so cumbersome or intrusive as to limit the guardian's ability to respond to the ward's daily needs in a timely and normal manner. Formal judicial review of specific decisions should occur where the consequences of a decision are of major importance or are irreversible.

BEHAVIOR MANAGEMENT

ISSUE

Behavior management programs may use a variety of teaching techniques to develop and maintain skills that will enhance an individual's opportunities for learning and self-fulfillment. The ARC recognizes that, regardless of the specific technique used, there is a potential for abuse and misuse of management procedures.

POSITION

The ARC supports behavior management pro-

grams for persons who are mentally retarded that are:

applied in a humane and caring manner with the ultimate goal of growth and habilitation,

intended to enhance opportunities for self-determination and independence,

based upon the thorough assessment of each individual's existing competencies and characteristics,

effective in developing competence to cope with the environment and fostering more complex adaptive behaviors,

implemented by a staff that is well-trained in the specific approach being used,

monitored continuously and systematically to ensure that the approach is consistent with individual needs and successful in achieving established goals.

based on a positive approach to the development and maintenance of desirable behavior, and

free from methods and techniques which can produce physical or psychological pain or discomfort. Aversive or punitive approaches may be considered only in those cases where (1) all alternative positive approaches have been properly attempted and documented as unsuccessful, and (2) it has been determined that the person's current unsuitable behavior constitutes imminent and serious danger to himself or herself, or to other individuals. Positive ap-

proaches to behavior management must continue to be used in conjunction with such techniques. Additionally, an oversight committee must be convened within a school or agency to evaluate the initial need for and continued appropriateness of aversive approaches.

QUALITY ASSURANCE

ISSUE

In recent years, this country has witnessed rapid expansion and diversification of services for people who are mentally retarded, resulting in more community-based programs, a move to smaller scale residential services, and a broader array of program options. This trend toward more stimulating, more normalizing experiences for people who are mentally retarded and the resulting dispersion of settings has intensified the need for effective methods to ensure the quality of services. Yet, while the need for quality assurance is generally accepted, the question of what constitutes "quality" remains open to broad interpretation. Some view "quality" as merely a judgment of whether a service is good or bad. Others perceive "quality" as principally a personal concept dependent upon the feelings and perceptions of the individual consumer, thus not readily subject to formalized measurement or definition. Still others view "quality" as a characteristic susceptible to formal measurement, but differ in their definition of what is to be measured and in approaches to its assessment.

In the case of human services, the issue of quality assurance generally has two particular ramifications for people who are mentally retarded. One is related to their specialized needs. The other is concerned with a common problem experienced by many people who are mentally retarded who, as consumers, encounter difficulty assessing

for themselves the value and benefit of a service. Because safeguarding the interests and well-being of consumers who are mentally retarded is an overriding concern, it is generally believed that the quality of programs and services must be operationally defined and translated into dimensions which are measurable to the maximum extent possible. Statements of measurable criteria generally are referred to as standards.

Compliance with standards may be mandatory as in the case of local and state fire safety codes, largely voluntary as exemplified by accreditation efforts, or a prerequisite to funding such as the federal standards for intermediate care facilities for people who are mentally retarded.

In the context of a quality assurance system, quality is generally viewed as a multidimensional concept, at times a general goal of programs and at others a concrete objective of a specific service. Most current approaches attempt a systems view, considering quality in terms of outcome, input or process dimensions of service, generally emphasizing one over the others. Each dimension has inherent strengths and weaknesses.

Outcome measures reflect what actually happens to a consumer who is mentally retarded as the result of receiving a specific service. Many prefer outcome measures since such assessments relate quality to actual concrete results of services, and thus are regarded as more directly related to the purposes of the activity or service. But in certain instances, outcome measures may be virtually impossible to obtain because valid measurement instruments have proven exceedingly difficult to devise. **Input measures** refer to quantity and quality of resources used in providing the service, such as staff qualifications, staffing ratios, nutritional content of food and the condition of physical facilities. However, while input measures are more easily devised and employed, research results may not be available to verify a firm causal relationship between input and service outcomes. **Process measures** refer to assessment of the methods by which services are provided, including the in-

teractions between the service provider and the consumer who is mentally retarded. Examples include the use of written individual program plans with objectives stated in behavioral terms; the use of an interdisciplinary team process that includes participation of the client and, as appropriate, the client's parents, guardian, or advocate; minimizing the use of behavior management drugs (because such drugs regardless of the beneficial effects they may have, also have negative effects on learning); and providing services in normalized settings (because such settings promote culturally normative behavior). These processes should be implemented because they are directly and empirically related to desired outcomes. The use of any process measure should be justified by such a relationship.

The development of quality assurance approaches is still in the early stages. Fragmentation, gaps, duplication and overlaps continue to exist. The extent to which a quality assurance system can effectively meet its goals is generally believed to rest with the process of setting standards, monitoring and evaluating results and establishing consequences of performance, (i.e., incentives for compliance and, conversely, disincentives for non-compliance.)

POSITION

The ARC views quality services as those which are provided in a humane manner and produce growth and development in people who are mentally retarded.

The ARC advocates use of outcome measures (where available and applicable) as preferable to input and process measures in selecting dimensions of service to be employed in a quality assurance system. While outcome measures are favored, the structural aspects of service delivery (input measures) and the manner in which services are provided (process measures) cannot be overlooked or ignored as unimportant. However, input and process measures of quality should be

employed only when shown to be positively correlated with desired consumer or program outcomes.

The ARC views the development of appropriate standards as a key factor in designing an effective quality assurance system. Standards should bear a verifiable relationship to service goals and should furnish measures of growth and development of consumers, responsiveness of services to individual needs, consumer satisfaction, quality of the environment in which services are delivered, safety and well-being of consumers and efficiency of the services provided. Furthermore, standards should be consistent, flexible, clear and measurable. Consistency is essential to assuring compatibility among program requirements, thereby reducing the potential for conflicting mandates and the burdensome duplication and overlap which render some efforts at quality assurance unacceptable. Flexibility allows for application in a variety of program contexts, thus permitting the use of creative service methods. Clarity defines intent, reducing or eliminating the likelihood of misinterpretation. Measurability provides for a determination of whether or not a standard has been achieved. Standards themselves should be reviewed and revised periodically in light of new developments in knowledge and technology.

The ARC views program monitoring and evaluation as an essential component in a quality assurance system. While it is neither feasible nor desirable to have this function performed comprehensively for all components by a single entity, and while self-assessment is strongly encouraged, principal responsibility for monitoring and evaluation must be vested with bodies independent of the particular service delivery system in order to preserve the integrity and validity of the quality assurance effort. Monitoring and evaluation efforts conducted by different agencies should be coordinated in order to make best use of the time and resources of the service provider.

The ARC believes an effective quality assurance system must provide incentives for good perfor-

mance and disincentives for poor performance. Such consequences may assume many forms including, among others, approval or sanctions, accreditation or decertification. In addition, performance should have implications for future funding.

REFERENCES

- Bellamy, T., Peterson, L., and Close, D. *Habilitation of the severely and profoundly retarded: Illustrations of competence, education and training of the mentally retarded.* 1975, 10, 174-186.
- Crosson, J. *The experimental analysis of vocational behavior in severely retarded males.* Doctorial dissertation, University of Oregon, 1966. Abst. Int. 27:3304.
- Flynn, R., and Nitsch, K. *Normalization, social integration and community services.* Baltimore: University Park Press, 7-30, 1980.
- Gold, M. *Stimulus factors in skill training of the retarded on a complex assembly task: Acquisition, transfer and retention.* American Journal of Mental Deficiency, 1972, 76, 517-526.
- Loos, F., and Tizard, J. *The employment of adult imbeciles in a hospital workshop.* American Journal of Mental Deficiency, 1955, 59, 395-403.

Naisbitt, J. *Megatrends: Ten new directions transforming our lives*. Warner Books, Inc. New York, 1982.

Wolfensberger, W. *A brief overview of the normalization principle in normalization, social integration and community services*. Flynn, R., and Nitsch, K. (Eds.). Baltimore: University Park Press, 1980.